Online information and support needs of women with advanced breast cancer: A qualitative analysis.

Running Title: Online information and support needs of women with advanced breast cancer

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Abstract

Purpose

Women with advanced breast cancer (ABC) face significant adjustment challenges, yet few resources provide them with information and support, and attendance barriers can preclude access to face to face psychosocial support. This paper reports on two qualitative studies examining (i) whether information and support-seeking preferences of women with ABC could be addressed in an online intervention, and (ii) how an existing intervention for patients with early stage cancer could be adapted for women with ABC.

Methods

Women with ABC participated in telephone interviews about their information and support-seeking preferences (N = 21) and evaluated an online intervention focused on early-stage cancer (N = 15). Interviews were transcribed and underwent thematic analysis using the framework method to identify salient themes.

Results

Participants most commonly sought medical, lifestyle-related, and practical information/support; however, when presented with an online intervention, participants most commonly gave positive feedback on content on coping with emotional distress. Difficulty finding information and barriers to using common sources of information/support including health professionals, family and friends, and peers were reported; however, some women also reported not wanting information or support. All participants evaluating the existing intervention gave positive feedback on various components, with results suggesting an online intervention could be an effective means of providing information/support to women with ABC, given improved specificity/relevance to ABC and increased tailoring to individuals circumstances and preferences.

Conclusions

Adaptation of an existing online intervention for early stage cancer appears a promising avenue to address the information and support needs of women with ABC.

Despite evidence of high distress [1, 2] and high support needs [3], women with advanced breast cancer (ABC) report frequent unmet needs. A 2015 Breast Cancer Network Australia (BCNA) online survey of 582 individuals with ABC [4] found unmet needs in up to 68% of participants, with five of the top 10 domains relating to psychosocial needs, and recommended addressing these needs through development of specific resources for women with ABC [4].

A 2013 Cochrane Review found only 10 randomised controlled trials (RCTs) of interventions for women with ABC [5]; these predominantly evaluated intensive face-to-face group therapy programs requiring weekly participation [5]. Our subsequent systematic review found a strong evidence base for efficacy of face-to-face group therapy for ABC but lower accessibility and/or acceptability [6], consistent with previously documented low uptake of face-to-face mental health services among women with ABC [7, 8]. Both reviews recommended future research should focus on accessible low-intensity, home-based interventions, such as tele- or internet-based counselling, specifically to meet needs of women with ABC [5, 6].

While web-based therapy is yet to be tested in ABC, our group developed and extensively tested a web-based psychological intervention for *early-stage* cancer patients [9]. This has consistently demonstrated improvements in quality of life and psychological distress, with a multi-site RCT finding reduced health-service utilisation [9-12]. While designed for the curative setting, this program may offer a useful basis for developing an ABC-tailored adaptation.

Co-design of an online program tailored to women with ABC requires exploration of information and support needs of women with ABC *that may be met via an internet intervention*. Thus, women's preferences for internet use, and experiences of the internet intervention format, require examination.

Cross-sectional surveys have found frequently reported unmet needs of women with ABC include psychological, informational, and practical needs (e.g. [4, 13-16]). Qualitative studies highlight concerns about treatment side-effects, body image, sexuality, fear of disease progression and dying, lack of social support, ambivalence over support group use, and preferences for seeking alternative means of support [17, 18]. However, few studies examine whether such needs and concerns can be addressed via the internet.

Studies of internet use by women with *breast cancer* report predictors of internet use (e.g. younger age, higher education [19-21]); reasons for not using the internet (e.g. lack of computer/internet access, satisfaction with provided information, and fear of what internet information might say [20]); no association of internet use with coping [22]; and reasons for discussing internet-obtained information with doctors (e.g. becoming more educated [23]). Studies reporting *types* of information sought are rare; one study reported women with *breast cancer* most commonly seek medical information [21], and one indicated women with *ABC* sometimes used internet to check symptoms were normal but preferred other information sources [18]. To our knowledge, no other study has specifically explored patterns of internet use among women with ABC to meet information and support needs, nor has any study examined perspectives of women with ABC regarding development of an ABC-specific internet intervention, nor obtained evaluative feedback of an existing internet intervention.

This paper summarises two related qualitative interview studies that investigate this unexplored area by examining information and support needs of women with ABC *that could be addressed in an online intervention*, and preferences for the content and format of such an intervention (Study 1), and exploring the views of women with ABC on the existing *Finding My Way* (*FMW)* program, to identify whether it is broadly applicable to this setting, and identify how content might require revision (Study 2).

Method

Participants

Participants were 21 women with ABC, aged 34 to 78 years (M = 59.71, SD = 10.50), recruited via clinicians at Flinders Centre for Innovation in Cancer (N = 16) or online promotion through Breast Cancer Network Australia (N = 5) (study 1); and 15 women with ABC and internet access, aged 42 to 69 years (M = 58.80, SD = 7.50), recruited via Study 1 (N = 9), or subsequent BCNA promotion (N = 6) (study 2).

Materials

Study 1 participants were sent a semi-structured interview guide to allow them to consider their information and support-seeking preferences prior to participating in interviews. The guide consisted of nine questions regarding current information and support-seeking, how successful participants found their efforts to seek information/support, and attitudes toward using the internet to seek information and/or support for ABC. The *interviewer* version of the guide included additional prompts to facilitate responses where required.

Study 2 participants received access to *FMW*, a 6-module online psychological intervention designed for individuals with curatively treated cancer of any type [9], with all modules simultaneously available for review. Prior to interviews, they were also sent a semi-structured interview topic guide comprising two sections: (1) general program feedback (11 questions), and (2) specific feedback on the user home screen and each of the six modules (Appendix 2).

Procedure

Ethics approval was obtained from Southern Adelaide Clinical Human Research Ethics Committee. All interviews occurred via telephone and were audio-recorded, then transcribed. Saturation was determined through an iterative process; after completing the 20^{th}-21^{st} interviews (Study 1) and 14^{th}-15^{th} interviews (Study 2), no additional issues were being identified and no new themes were emerging; collection of further data was therefore determined redundant.

Analysis

Transcripts were thematically analysed using the software program NVivo 11 to identify salient themes and subthemes. Due to the pragmatic objective of informing future development/adaptation of an online intervention, themes were developed as per the framework method of thematic analysis [24] in response to the specific objectives of the study. While themes were qualitatively developed, they were summarised according to *prevalence* (how many participants raised a theme), and *frequency* (how many times in total a theme was raised).

Results

Numerous themes were identified for both studies, therefore only the most prevalent are reported here. For a detailed summary of all themes and subthemes (including frequency and prevalence) please refer to Appendices 3 and 4.

Information and support needs (Study 1)
Themes clustered under five broad areas of information/support sought, sources, barriers to information and support seeking, content, and attitudes to internet (Figure 1, and see Appendix 3).

Participants most commonly reported **seeking** medical information, particularly on treatment and side-effects, diagnosis/prognosis, and new interventions. For example:

> 'For me, it was more about the longevity. How long was the median life, you know?' (Participant 16).

Approximately one third sought information or support for lifestyle choices, including diet and other lifestyle choices; and one third sought practical information/support, including financial and functional information/support.

A small minority of participants (14-19%) sought others' experiences of ABC, information or support for end-of-life decisions/arrangements, or emotional/psychological support.

Most commonly reported **information/support sources** included family and friends, medical/health professionals and print resources. Peer support from others with ABC or other cancers was a source of support for almost half of the participants and included informal peer support and traditional or online support groups. Additional information and/or support sources included cancer support organisations, with professional psychology or counselling reported by a small minority. In addition to those reporting online support group use, *almost half of the participants reported using the internet to seek information and/or support for ABC.*

The most commonly cited **barrier to obtaining information/support** was difficulty finding information and/or support, reported by two thirds of participants, often due to a reported lack of ABC-specific information/support or difficulty meeting information/support needs through medical professionals. For example:

> 'There's lot about…early stages, but not a lot for stage four' (Participant 16)

Almost 25% of participants reported difficulty accessing services. Three participants noted difficulty finding information/support for partners/families while two noted particular challenges for rural patients in finding accessible information and/or support.

However, almost two thirds of participants reported not wanting some types of information/support. Specific reasons for this included not looking for emotional/psychological support, not liking psychology or counselling, and finding ABC-related information too confronting.

Over one third of participants reported the barrier of family and friends not meeting support needs; most experiencing this barrier had difficulty even discussing cancer with family and friends, which exacerbated limitations to information/support. For instance:

> 'I wanted to keep it to myself, to protect my family, so I didn't get the help I should have gotten for a long time' (Participant 18).

Participants also identified barriers to obtaining peer support. The majority reported not using a support group; with barriers including the sentiment that support groups were not 'their thing', lack of availability/access, not 'fitting in' due to most or all other women in the group having an early stage rather than advanced diagnosis, and the potential to be distressed by such groups. Differences between early and advanced breast cancer were also experienced as affecting the relevance of peer support more generally (including informal support).

Further barriers included challenges of timing with other life events/stressors and with cancer diagnosis and treatment.

The most commonly **suggested content** was medical information, including information on treatments and side-effects and on prognosis and 'what to expect'.

One third of participants wanted advice on accessing support, including up-to-date web links. Almost one third wanted lifestyle-related information/support.

One third suggested an online group and one third suggested content on others' experiences of ABC. Small minorities suggested emotional/psychological support, resources for/about partners and families, or information and support for asking questions and self-advocating.

Participants recognised **several advantages of using the internet** for ABC information and support, including general helpfulness of the internet, access to information/support in one's own time, and convenience of access. Over one third recognised potential advantages of an ABC-specific program, including centralisation of ABC-specific information and/or support, legitimacy of content, and convenience.

Several participants also noted that accessibility of the internet and of a specific program would be particularly helpful for rural people:

'Oh, country people just live on the internet. You see, that's the other thing, I think country people or rural people are more likely to use it than someone from the city' (Participant 3).

Despite recognising advantages, almost two thirds of participants **expressed concerns** about using the internet for ABC information/support, including concerns over legitimacy/currency of information, that information could be too confronting (including specific concerns over sensitive provision of palliative care information), and privacy. Frequently participants saw some advantages as well as disadvantages to use. However, over a third of the sample reported they would not have concerns about using a *specific* program for ABC information and support.

Participants noted individual differences in information- and support-seeking preferences between women with ABC, including a minority who stated preference for face-to-face support. Several participants reflected that information/support needs could vary according to

differences in prognosis, progression and response to treatment; thus, how to maintain relevance to all was a concern for some.

While a third of participants reported they were comfortable using the internet/computers, nearly as many stated they did not use the internet much.

Feedback on existing online resource (Study 2)
Themes in participant's evaluations of *FMW* are summarised in Figure 2 (for detailed description see Appendix 4).

Positive feedback on FMW content included participants' reflections that *FMW* is generally helpful or relevant.

Participants gave positive feedback on specific content areas, most commonly content on emotional distress, worksheets/exercises, and meditation/relaxation, but also content on clarifying questions, supporting partners and families, physical symptoms, and self and identity, along with video content and anecdotes. Over one third of participants commented that some content was relevant to ABC despite the early stage cancer focus.

The most common **recommended change to content** was increasing relevance to ABC. Specifically, participants indicated a need for content to address issues of ongoing/progressing treatment (instead of treatment completion), and recommended this content address both end-of-life treatment decisions and care, and coping psychologically with mortality, for example;

> 'When you reach stage 4, the biggest thing on your mind is the fear of dying. You know, that fear hits you like a brick wall. That's really, *really*, hard, to get through…and that is really what I would call a top lying thing that needs to be addressed, the mortality.' (Participant 5).

More than half commented that women with ABC who have previously had early stage disease are already familiar with FMW content, thus reducing relevance to ABC. While one participant with a de novo diagnosis of ABC reported experiencing a knowledge gap compared to women who had progressed after early stage diagnosis, two participants raised the potential for women with a de novo ABC diagnosis to be overwhelmed by too much information.

Specific content that participants did not relate to most commonly included worksheets/activities, for example:

'The thing that put me off was the homework, the exercises and homework.' (Participant 12).

However, recommended changes more commonly involved suggested additional content, most often on accessing available resources and coping with partner, family and friend responses, along with treatment and side effects, exercise, and managing pain.

Feedback on use included themes reflecting finding the intervention easy to use, improvements needed to use/navigation, issues for use and access, and issues in information and support seeking for women with ABC.

Almost all participants found *FMW* easy to use. Specific factors identified as facilitating ease of use included appropriate language, sufficient flexibility/self-pacing, appropriate module length, a well set-up home screen, and ease of the internet format.

Comments on improvements related to *FMW* needing general improvement to ease-of-use or specific navigation/layout issues, or evaluations that the program/modules were too long, needed more flexibility for self-pacing, needed better indexing, or were too complicated. Four participants noted difficulty focusing after recent treatment or being informed of progression.

Issues for use and access included participants' recognition that the intervention would need to be well-promoted, and would need to be kept relevant and up to date.

Participants' recognition that every woman with ABC was different included recognition of varying preferences for information and support seeking among women with ABC, with three participants reporting preference for face-to-face support; and recognising that some women with ABC may have difficulty using technology. One participant commented on varying disease-related needs and (response to) treatment, and on coping with guilt on comparing oneself with others' needs or responses.

Finally, participants' evaluations revealed the general but pervasive issue in information and support-seeking for women with ABC, that ***more support is needed for ABC***. This included reports of feeling unsupported with ABC, the need for more studies of women with ABC, issues around terminology reflecting ABC status (e.g. 'palliative', 'survivor'), and the need for more public awareness of ABC.

Discussion

The present studies found information and support commonly sought by women with ABC to include medical, lifestyle, and practical information/support, consistent with findings indicating highest levels of unmet need in women with ABC include health system and information domains [14-16] and use of internet among women with breast cancer to seek medical information [21].

Only a minority of Study 1 participants reported seeking psychological/emotional information/support despite unmet needs in the psychological domain being commonly identified in previous studies [14, 15]. Participants may have had these needs met informally, and therefore may not have considered themselves as actively seeking psychological/emotional support. On the other hand, participants may have perceived psychological information/support as involving a traditional support group or face-to-face therapy, or did not expect to find relevant psychological/emotional support for ABC, and therefore did not look despite their need.

It may be the case that psychological distress and unmet needs in women with ABC could be addressed by meeting their information needs, and providing greater opportunities to learn from peers, or that internet is not perceived as the medium through which women address emotional needs.

Interestingly, when presented with an example intervention, the majority of Study 2 participants gave positive feedback on content concerning emotional distress and

worksheets/activities, and more than one third gave positive feedback on meditation and relaxation content; these three content areas were the top three that received specific positive feedback. One third also suggested relevance to ABC would be increased by addressing coping psychologically with mortality. Therefore, it appears women with ABC respond positively to an *online* avenue for addressing psychological/emotional needs but may not be aware of the potential of internet in addressing that need.

Together these findings offer new insights into how women with ABC perceive the role of the internet in addressing their support needs in terms of preferred content and pattern of use. The study offers some suggestion that women may not realise the full potential of what internet may offer, or may have particular preferences regarding content or type of support obtained via internet. These observations warrant further research.

Notably, participants drew on family support but reported a lack of resources available to families, consistent with research indicating high levels of burden and low levels of available support for cancer caregivers/signficant others [25]. At times participants attempted to fulfil partner/family support needs or prioritised family needs over their own. Concern for families and friends also contributed to difficulty obtaining support due to reluctance to discuss cancer with them.

Difficulty finding ABC-specific information/support and feeling unsupported in comparison to available information and support for early stage breast cancer corroborate other recent findings that women with ABC believe ABC-related information is inadequate and frequently feel isolated [13].

Findings suggest women with ABC could see benefits of a specific internet program, *provided* it was legitimate, up-to-date, and ABC-specific. Most Study 2 participants noted *FMW* needed more specificity to ABC, and several suggested tailored sections for women who received a de novo diagnosis of ABC, reflecting BCNA recommendations [4]. Variation in specific content areas participants related to and concerns over whether ABC-related information may be confronting or stressful also highlighted the importance of personalising the intervention to address varying needs of women with different disease-related and other circumstances, consistent with literature indicating benefits of tailored web-based interventions [26].

Limitations and directions for future research

While each study achieved saturation of themes, recruitment through BCNA online promotion and the Study 2 requirement of internet access may mean findings are biased toward perspectives of women with BCNA support and internet access. However, Study 1 included several women without internet access, and Study 2 included women who did not consider themselves technologically adept despite internet access. Furthermore, these studies are likely to represent perspectives of women most likely to access a future internet intervention.

Future research is required to develop and evaluate an ABC-specific internet intervention as a promising avenue for addressing the information and support needs of women with ABC, while also addressing how to provide accessible interventions to women who cannot, or are reluctant to, access the internet.

Conclusions

These studies confirmed that while many women with ABC are positive about an online intervention and would potentially use such an intervention to meet information and support needs, content of such an intervention needs to be ABC-specific, user-friendly, and personalised to suit users with a range of disease characteristics, treatments, personal circumstances, topics of interest, and information and support-seeking preferences.

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Compliance with ethical standards

Conflict of Interest: All authors declare no conflict of interest.

Ethical approval: All procedures in studies involving human participants were conducted in accordance with the ethical standards of the Southern Adelaide Clinical Human Research Ethics Committee, and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

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Figure 1: Summary of Study 1 Themes

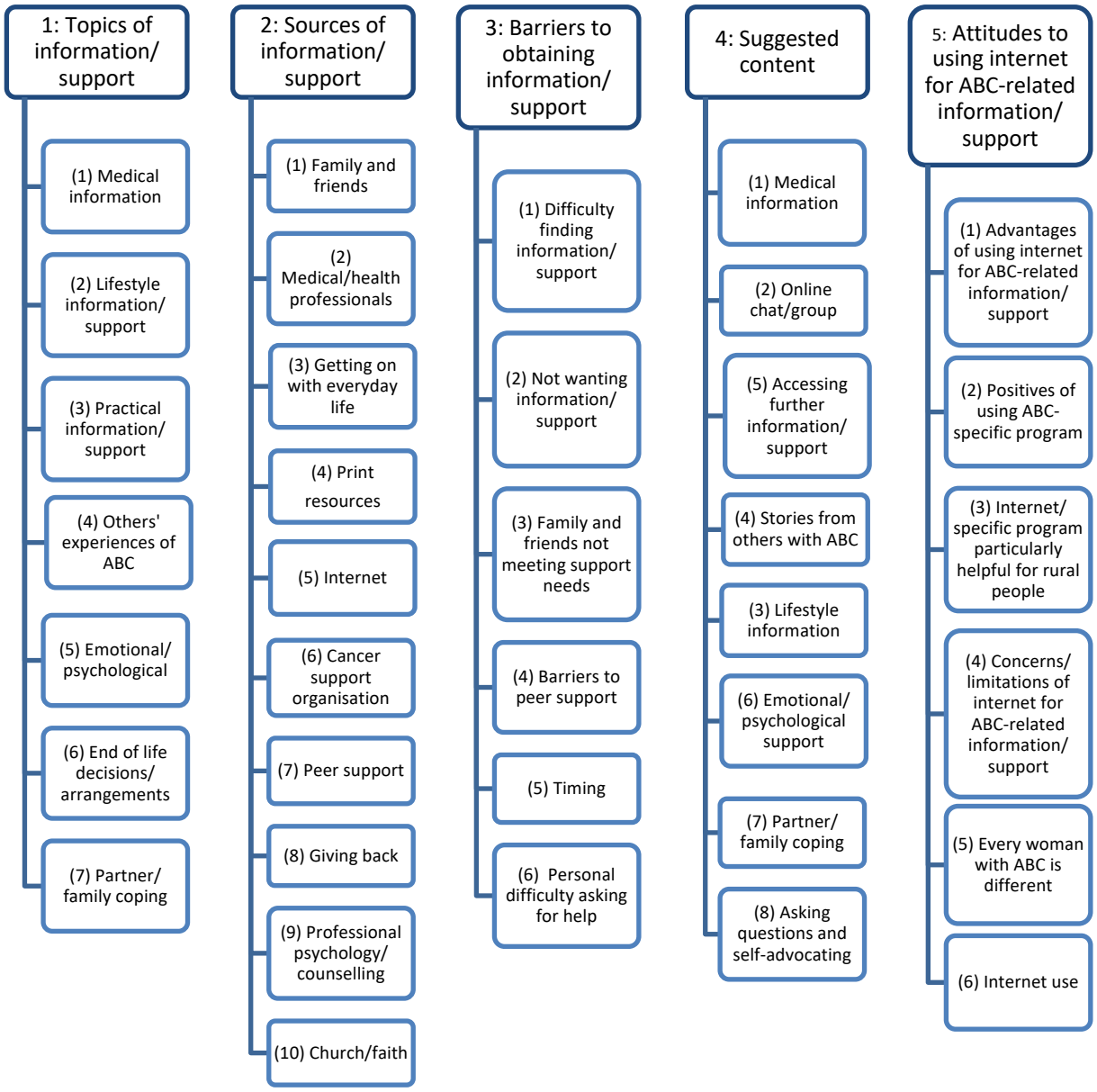
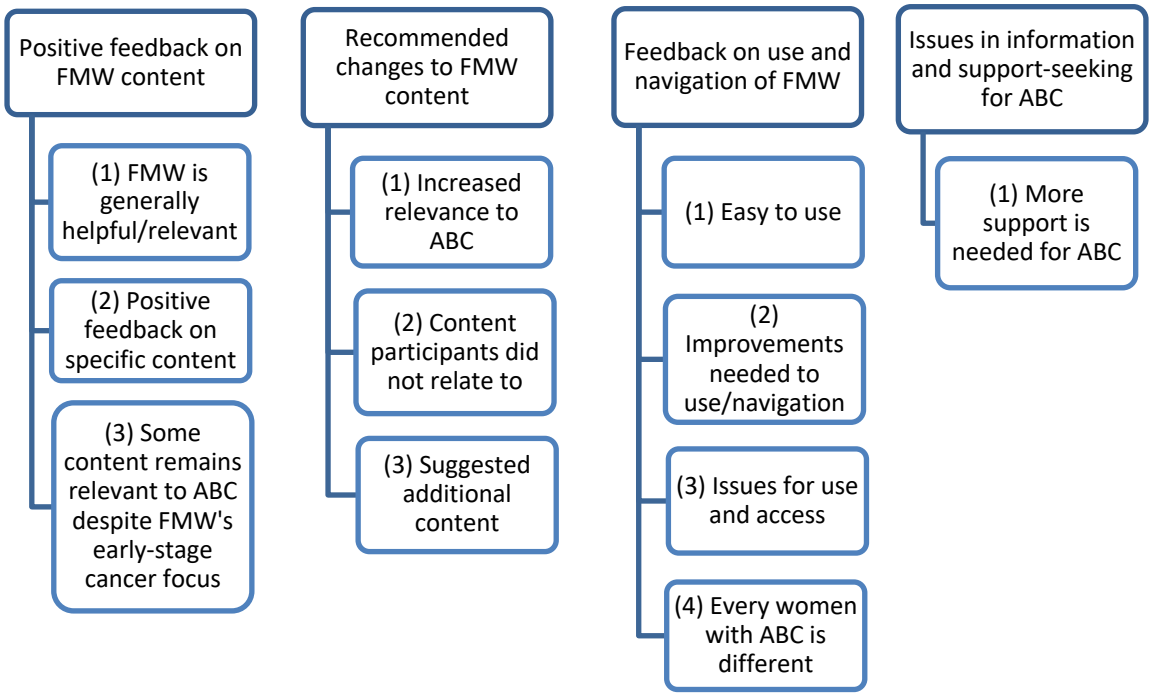


Figure 2: Summary of Study 2 Themes



Appendix A

***Finding My Way – Advanced*: Adapting an internet self-help coping program for women with metastatic breast cancer**

Interview topic guide

1. To get us started, please tell us your first name, something about yourself and something about your cancer journey.

2. People who have been diagnosed with cancer often feel that they would like more information or support for coping with their diagnosis. In what ways (if any) do you currently try to meet your needs for information, to cope with your breast cancer diagnosis?

(Prompt: do you look at written, online resources, support groups, discussions with friends, health professionals?)

3. In what ways (if any) do you currently try to meet your support needs?

(Prompt: do you look at written, online resources, support groups, discussions with friends, health professionals?)

4. What topics of information or support for coping with breast cancer have you looked for?

(E.g. medical information about your cancer, how to cope with practical challenges, emotional/psychological support, experiences of others with the same diagnosis).

5. How successful have you found your efforts to find information and/or support?

6. How do you feel about using the internet to look for information and/or support for coping with breast cancer?

(Prompts: useful/not useful? Do you find it easy to navigate the internet? Is it convenient? Do you have any concerns about using the internet to look for information/support?)

7. In your opinion, how could an internet program be an effective/suitable way of receiving information and/or support for coping with advanced breast cancer?

8. If you were provided with such a program, what kinds of information and/or support would you like to see included in it?

9. What concerns (if any) do you think you might have about using such a program?

(Prompt: what barriers (if any) do you think might prevent you from using such a program?)

10. *(Debriefing) We really appreciate your/this group's willingness to talk about these issues, and we understand that sometimes discussing cancer-related issues can lead to feeling some emotional discomfort. If you would like us/a psychologist from the FCIC clinic to provide a follow-up phone call at some point during the next couple of days to talk about any concerns, please come and see us after this session, or feel free to get in touch with us on the contact details provided on your information sheet in order to schedule a phone call.*

Appendix 2

Finding My Way – Advanced: Adapting an internet self-help program for women with metastatic breast cancer

EVALUATION

Topic Guide

Overall:

- What were your overall impressions of this program?

Use/ease of use

- What was your experience of navigating the program? (i.e., to go from page to page, clicking on modules & activities etc.)

- How did you find the length of the modules?

- How did you find the language used in the program?

- What factors, if any, prevented you from using the program as much as you thought you would/as much as you would have liked to?

- How would you suggest overcoming these factors for other women with advanced breast cancer?

Suitability of program content

- How did you find the content of this program (e.g. helpful/unhelpful; informative / irrelevant)
    - How did you find the information?

- How did you find the worksheets and suggested activities (e.g. relaxation exercises)?

- What was missing? (e.g., any particular information / resource)?

- Which parts of the program were most helpful to you? Why? (For example, which parts of the program did you relate to most?)

- Which parts of the program were least helpful? Why? For example:
  - Were there parts that were difficult to relate to?

  - Were there any aspects of the program that put you off?

- If you could make just one change to this program to make it a helpful resource for women with advanced breast cancer, what would it be?

- How likely would you be to use this type of program (if it was modified to be specific to your experience with advanced breast cancer)?

Debriefing:

- We really appreciate your willingness to talk about these issues, and we understand that sometimes discussing cancer-related issues can lead to feeling some emotional discomfort or distress. Would you like a follow-up phone call from a psychologist at some point over the next couple of days, to talk about any concerns?

Feasibility of online self-help therapy for individuals affected by advanced breast cancer

Module-by-module feedback

Module/Screen	What was good?	What needs changing?
User Home Screen		
1: Diagnosis		
2: Physical Symptoms		
3: Emotional Distress		
4: How You See Yourself		
5: Your Family and Friends		
6: Completing Treatment		

Feasibility of online self-help therapy for individuals affected by advanced breast cancer

Appendix 3: Study 1 themes and subthemes: definitions and examples

Topics of information and support looked for (7 themes)		
Theme/subtheme	Definition	Example
Medical information 18 participants, 48 references	Indicates participant seeks/ sought medical information/support, either in general, or as per subthemes	'Mainly for medical information' (p17)
Treatments and side-effects 12 participants, 26 references	Refers to information/support on available treatments and side-effects/for coping with side effects	'My main aim is just looking for the side-effects for the chemo' (p1)
Diagnosis and prognosis 10 participants, 15 references	Refers to information/support on what ABC is/specifics of individual diagnosis/potential trajectory of illness and life expectancy given that diagnosis	'For me it was…about the longevity. How long was the median life, you know? How long were people expected to live? What sort of things could I expect…to happen to myself…' (p16)
New interventions 2 participants, 2 references	Refers to information on/links to new trials/studies/breakthrough treatments	'What the new treatments are, what they're discovering…never giving up hope.' (p3)
Lifestyle 8 participants, 15 references	Indicates participant seeks/sought information/support on impact of lifestyle choices on ABC	
Dietary information 5 participants, 8 references	Refers to dietary information/support	'At the moment I'm looking at some DVDs…they have different people talking about your diet and all of the things that are in the foods that you eat today.' (p1)
Other lifestyle choices 4 participants, 7 references	Refers to information/support on lifestyle choices in general/other lifestyle choices e.g. exercise	'What can I do to get the best outcome.' (p5)
Practical 7 participants, 14 references	Indicates participant seeks/sought information/support to cope with practical issues	
Financial information/support 4 participants, 10 references	Refers to financial issues such as accessing financial assistance and superannuation	'Also… 'coz we had to spend six weeks down in Brisbane while I had radiation and we still had a house that we had to maintain…so we had to source information about financial help' (p21)
Functional information/support 4 participants, 4 references	Refers to everyday functional and domestic issues	'My doctor has said that I could lose function of my bowel and my bladder… what does that mean for…my life, and how do I cope with those sorts of things once that happens' (p16)
Others' experiences of ABC 4 participants, 6 references	Indicates participant seeks/sought stories, anecdotes or direct recommendations from others diagnosed with ABC	'The forums were interesting because they had other people going through exactly the same thing…they were dealing with the same thing and some of those people had…lived longer, what I was actually hoping for...' (p6)
Emotional/psychological support 3 participants, 5 references	Indicates participant seeks/sought information/support to cope emotionally/psychologically with ABC	It's just mainly a mental issue with me, trying to learn how to live…that's difficult…So it's like, it's a learning process of how you…live from day to day" (p14)

End of life decisions, arrangements 3 participants, 4 references	Indicates participant seeks/sought information/support for making end-of-life decisions/arrangements	'At the moment we're looking at end stage cancer…going through the whole interim power of attorney and all of that…' (p21)
Partner/family coping, support 1 participant, 4 references	Indicates participant seeks/sought information/support for coping with partner/family responses or assisting partner/family to cope	'I was always looking for how I can get my daughter some help. And now more recently how I can get my husband help'(p5)
Sources of information/support (10 themes)		
Theme/subtheme	Definition	Example
Family and friends 16 participants, 41 references	Identifies family in general, family member/s or friends/social group as source of information /support	'I've got a great group of friends…also my husband is amazing. He's been through cancer himself…so he has a little bit of understanding what's going on.' (p15)
Health professionals 15 participants, 50 references	Identifies health professional e.g. doctor/specialist, breast care nurse as source of information/support	'When I go to the oncologist … each time I go I probably ask more questions.' (p10)
Print resources 10 participants, 15 references	Refers to using print resources for information/support	'I picked up some brochures at the Cancer Centre to read.' (p15)
Peer support 9 participants, 26 references	Refers to obtaining information/support from others with ABC, breast cancer, or other cancers, as per subthemes	
Informal peer support 5 participants, 8 references	Obtaining information/support from others with ABC/other cancer in informal setting (e.g. waiting room)	
Online groups/forums 4 participants, 10 references	Joining/using online ABC group or forum for information/support	
Traditional support groups 4 participants, 8 references	Using 'face to face' or telephone support group for information/support	
Internet 9 participants, 12 references	Refers to seeking information/support on internet (not including online group)	'I searched on Google a lot, on the internet.' (p16)
Cancer support organisations 8 participants, 17 references	Refers to using cancer support organisation (e.g. BCNA, Cancer Council) as source of information/support	'The BCNA - I'm a member of that and they are a good support network as well.' (p21)
Professional psychology/counselling 4 participants, 7 references	Refers to obtaining information/support from psychologist or counsellor	'I've got a psychologist who I speak to once a month..' (p7)
'Giving back' 3 participants, 13 references	Refers to 'giving back' to others, providing information/support to others, as a positive strategy	'Then, you know, you've got that opportunity to give back when you're feeling better.' (p1)
Church/faith 3 participants, 5 references	Refers to obtaining information/support from church community or faith/spirituality	'And I also have very strong faith, so I sourced help from my church' (p21)
Barriers to information/support-seeking (6 themes)		
Theme/subtheme	Definition	Example
Difficulty finding information/support 14 participants, 112 references	Indicates difficulty/frustration in seeking, or a lack of available, information/support …	
Lack of ABC-specific information or support 9 participants, 20 references	…that is ABC-specific	'There's not a lot about metastatic breast cancer. There's lot about…the early stages, but not a lot for stage four.' (p16)

Difficulty meeting information/support needs through medical professionals 8 participants, 28 references	…through medical professionals, e.g. doctor, specialist	'And my oncologist is brilliant, but very busy. And if I ask all the questions that I want answered, I might be there, like, forever. And he hasn't got the time for that.' (p17)
General difficulty searching for information 5 participants, 23 references	…in general	'That information may be there somewhere…but unless someone gives you the link or exactly where to go or, it's really, you know, if you go to search it and it comes up straight away, you can't find it.' (p3)
Difficulty accessing services 5 participants, 20 references	…to do with accessing or finding out about available services	'I'd say…I need someone to help clean. Oh, yes, that's fine….I qualified every single thing. And then they'd say how old are you dear? At this stage it was 58. And they went: "Oh, no I'm sorry. You're too young." ' (p4)
Difficulty finding information or support for helping partner, family 3 participants, 13 references	…for, or about coping with the responses of, partners and other family members	'No, there's nothing out there really that actually gives you information, um, on how to deal with them… while reassuring them I'm not going anywhere fast...' (p4)
Challenges for rural cancer patients accessing information/support 2 participants, 8 references	…that is relevant/useful to people residing in rural areas	'I know there's Cancer Council or whatever they're called. They are pretty good, but they're not, they still don't…Rural, for rural people, it's really difficult.' (p3)
Not wanting information/support 13 participants, 45 references	Indicates participant is not seeking information/support other than that routinely provided, due to either perceived general lack of need or specific reasons as per subthemes	'I don't feel that I need to get more information about it because…I can cope with it.' p11)
Not looking for emotional/psychological support 5 participants, 6 references	Refers to not wanting/needing emotional/psychological support	'I haven't really felt that I need to have any of that' (p19)
Not liking psychology/counselling 4 participants, 10 references	Refers to not liking or not having prior success with professional psychology/counselling services	'Psychologist at one time only. She wasn't that successful.' (p14)
Finding ABC-related information too confronting 2 participants, 4 references	Refers to avoiding/not seeking ABC-related information/support due to finding it too confronting or scary	'I don't really go for information anymore because it's too scary.' (p5)
Family and friends not meeting support needs 6 participants, 10 references	Indicates difficulty/frustration in obtaining support from family or friends	'My daughter thinks she knows… more about what is happening to me than I do. So, she's not much use, 'coz, you know, you're talking to somebody who thinks they know everything' (p17)
Difficulty discussing cancer with family/friends 5 participants, 16 references	Indicates difficulty/reluctance discussing or bringing up ABC with family or friends, including due to desire to protect family/friends	'I don't like to talk about it too much with the family because I feel I'm putting too much pressure on them and I don't wanna do that…I try and act like there's nothing going on.' (p14)

Barriers to obtaining peer support 13 participants, 22 references	Indicates difficulty/frustration in obtaining peer support from others with ABC/breast cancer/other cancer	
Not using support group 12 participants, 17 references	Describes not using a support group, in general or for reasons described by subthemes	
• *Not 'their thing'* 4 participants, 5 references		'No, I'm quite happy on my own and in my own space.' (p7)
• *Lack of availability/access* 4 participants, 4 references		'I haven't done anything like that...'coz I don't know of any that are in [regional town]' (p16)
• *Potential to be distressed* 3 participants, 3 references		**'**I don't want to be surrounded by people who can get as down as I do, to be honest' (p17)
• *Not fitting in due to advanced diagnosis* 1 participant, 2 references		I was a reflection or a reminder to them of what can happen…I didn't feel that it was fair and I stopped going because it didn't offer me anything (p7)
Differences between early and advanced breast cancer 3 participants, 5 references	Indicates peer support is more helpful/relevant when peer is also diagnosed with ABC (as opposed to early breast cancer)	'They've gotta be the same. You have to be the same. It won't work otherwise.' (p14)
Never met another woman with ABC 3 participants, 5 references	Indicates participant has never to their knowledge met another woman diagnosed with ABC (as opposed to early breast cancer)	'I've met plenty of people that have had mastectomies… but not the continuous metastatic breast cancer...' (p1)
Timing 5 participants, 11 references	Indicates difficulty seeking or obtaining information/support due to timing of competing priorities/other issues	
Too busy with other life events/challenges 3 participants, 6 references	Refers to competing non-cancer related commitments/issues	I haven't been [meeting my needs]…there's been too many other things going on. Also my son…I've had all that to deal with as well. (p8)
Timing with cancer diagnosis and treatment 2 participants, 5 references	Refers to competing priorities related to cancer diagnosis, treatment, and/or side-effects	'All you're really doing is concentrating on trying to get well after your chemo. So, yeah, the first 12 months are really, it was a blur.' (p7)
Personal difficulty asking for help 2 participants, 2 references	Indicates difficulty obtaining information/support due to not liking/not being used to asking for help or support from others	I think the hardest things for anyone who is ill, very ill, is to say: "I need help." (p4)
Suggested content for ABC-specific program (8 themes)		
Theme/subtheme	Definition	Example
Medical information 11 participants, 37 references	Participants suggests program could/should include medical information falling under the following subthemes	
Treatment and side-effects 6 participants, 10 references		'How it's decided what treatment is the best for that stage or for

		you. You know, what types of treatment are available? (p4)
Prognosis, including end-of-life 5 participants, 11 references		'Wanting to know what's going to happen next… the scary part is not knowing what to do next. …at this stage now, you don't know what the next stage is.' (p16)
• *Palliative care* 1 participant, 2 references		'Maybe palliative care. Just, sort of, to reassure people a bit.' (p19)
Basic/general information on ABC 5 participants, 5 references		'I think if, for coping with advanced breast cancer, yes, I think you have to come out with the basic facts…' (p19)
Explanation of medical terminology 3 participants, 11 references		'Some terminology sometimes that you don't understand… you come away, think about it, you wanna have a bit of a look to see 'what's that all about'' (p2)
Online chat/group 7 participants, 15 references	Suggests program could/should include access to an interactive online group e.g. chat group, forum	'If there was some sort of online chat group that would be fantastic. Where we could get on and, you know, have a chat in real time.' (p16)
Accessing support 7 participants, 13 references	Suggests program could/should include information on/links to further options for support/support organisations	Just knowing that there's all the organisations out there that you can contact… information on all different things that people can access or do if they want to.' (p12)
Up to date links 3 participants, 4 references	Refers specifically to links to current support options or other ABC-related links e.g. trials	'Perhaps something that keeps you up to date with what's happening. (p7)
Others' experiences of ABC 7 participants, 10 references	Suggests program could/should include anecdotes or recommendations from others diagnosed with ABC	'Maybe the other people could put on an internet site what they did to help with side effects.' (p6)
Lifestyle 6 participants, 16 references	Suggests program could/should include information on/strategies for improving lifestyle to support living well with ABC	'low-impact exercises for people with this side-effects of fatigue and tiredness, because…you don't feel like going to the gym' (p1)
Emotional/psychological support 4 participants, 8 references	Suggests program could/should include information on/support for coping with emotional/ psychological impact of ABC	'So the things that you go through when you first get diagnosed…to know how to handle different things, like…your emotional roller coaster that you go on. To be able to handle depression when you get depressed sometimes.' (p15)
Resources for/about partners, families 2 participants, 4 references	Suggests program could/should include information on/strategies for helping partners/families to cope, or for coping with partner/family responses to ABC diagnosis	'The tricks that they've got for your family...suggestions, that sort of thing. Because, you don't live on an island, you know. You're surrounded by family and they need help too.' (p17)
Asking questions and self-advocating 2 participants, 4 references	Suggests program could/should include information on/strategies for asking questions and self-advocating within health system	'What questions should they be asking and that sort of thing…I think ladies my age… probably don't ask enough questions'(p10)
Attitudes to using the internet for ABC-related information/support (6 themes)		
Theme/subtheme	Definition	Example

Advantages of using internet (general) for ABC information/support 8 participants, 21 references	Indicates recognition of benefits of using internet in general to seek ABC-related information/support	
Generally helpful 5 participants, 11 references	Refers to general helpfulness of internet, or that it is 'good'	'It's helped me a lot' (p19)
Access in own time 4 participants, 7 references	Refers to advantage of being able to seek/obtain information/support in own time (i.e. not limited to opening hours, personal choice)	'You can look up information whenever you want… you can look up stuff without pressure.' (p14)
Convenience of access 3 participants, 3 references	Refers more generally to convenience, or being able to access internet easily	'It's just so convenient, I think it's the convenience' (p14)
Advantages of ABC-specific program 6 participants, 10 references	Indicates recognition of potential benefits of using a specific internet program to seek ABC-related information/support	
Specific information/support for women with ABC 2 participants, 4 references	Refers to benefit of being able to find specific ABC-related information and/or to being able to obtain such information in one place	'I do like the idea of what you're trying to do and it would be nice if the things that you need to know while you're going through this journey is all in one spot.' (p14)
Legitimacy of information/support 2 participants, 2 references	Refers to being able to know that the information provided was legitimate/correct for ABC	'That would be really good because we would know that we could trust it' (p9)
Convenience 2 participants, 2 references	Refers to more generally to convenience or ease of access (as per convenience of internet in general but referring to program)	'If you don't feel like talking, you can just look it up and read it without having to talk to someone or go out.' (p18)
Internet (program) particularly helpful for rural people 4 participants, 6 references	Indicates recognition of specific benefits of internet in general or an ABC-specific program for people diagnosed with ABC living rurally	'It would be absolutely invaluable for people in rural areas because they don't have stuff at their fingertips and they can't just…rock up to the local clinic because often there isn't one. So, an internet based resource, particularly for people in rural areas, would be fantastic.' (p21)
Concerns, limitations of internet (program) for ABC information/support 20 participants, 88 references	Describes potential concerns about using internet/ABC-specific program to seek ABC-related information/support	
Legitimacy/currency of information 13 participants, 36 references	Refers to concern that information/support provided is correct and up to date	'As long as that information is correct…that's what I'm concerned about.' (p14)
Information on internet too confronting 6 participants, 16 references	Refers to concern that information provided might be confronting or distressing to users	'They might be rather confronted by some of the things…they might then need to get some support from elsewhere to, kind of, balance that out a bit' (p19)
• *Need to provide palliative care information sensitively* 2 participants, 3 references	Refers to specific concern that palliative care information needs to be provided sensitively to avoid distressing users	'I think that's one area that…if you have a website and information online…has to be carefully updated and maybe addressed so that people don't feel too confronted by it….' (p19)

Concerns for users unfamiliar with internet/computers 5 participants, 11 references	Refers to concern that people unfamiliar with computers/internet might have difficulty	'People who aren't computer savvy would struggle with the chat.' (p17)
Privacy/security 4 participants, 8 references	Refers to concerns over maintaining privacy/security when using internet or ABC-specific program	'That was just one of the things that came into my head was the hackers or whatever they call those people' (p1)
Need to keep it simple 3 participants, 7 references	Refers to suggestions, or concerns over need for, a simple program so as not to overwhelm users	'For me, it would have to be something that wouldn't be over the top.' (p12)
No concerns for specific program 8 participants, 10 references	States no concerns over using a specific program, (assuming that privacy, legitimacy concerns etc. would be addressed by program)	'No, I don't think so. I'd be interested to see what you come up with…I don't think I'd have any concerns.' (p12)
Every woman with ABC is different 10 participants, 31 references	Refers to differences between wome	
Different information- and support-seeking preferences 9 participants, 20 references		'There's women out there that…wanna query things…and there's others that don't wanna know about it' (p14)
• *Preference for face-to-face support* 4 participants, 10 references		When I need…help and all that, I would rather have face to face human contact…Internet doesn't do too much for me.' (p13)
Different cancer progression and response to treatment 6 participants, 11 references		Everyone is different and their… cancer is different' (p12)
Internet use 14 participants, 32 references	Describes participant's usual or likely patterns of internet use	
Comfortable using internet, computers 7 participants, 8 references	Indicates comfort, ease, familiarity using computers and/or the internet	'I'm at ease with the internet.' (p15)
Doesn't use internet much 6 participants, 12 references	Indicates participant doesn't use the internet much or at all	'I don't know. Because I'm not into the internet…I don't do it' (p14)
Hasn't got reliable internet access 3 participants, 7 references	Indicates participant doesn't have access to the internet or if they have access it is not reliable	'We do have the internet…but every now and then it drops out…or goes slow which is just as frustrating.' (p17)
Uses internet but not for ABC 2 participants, 3 references	Indicates participant does not use internet to seek/obtain information/support for ABC	'No, not for information or anything like that.' (p11)
Would use an ABC-specific internet program 7 participants, 7 references	Indicates participant's own judgement that they would use a specific program to obtain ABC-specific information/support if such a program was available.	'If it was there, I probably would…because I know there's something there for me… I think I would…make myself attend it.' (p14)

Appendix 4: Study 2 themes and subthemes: definitions and examples

Feedback on content (15 participants, 447 references)		
Positive feedback on content (15 participants, 165 references)		
Theme/subtheme	Definition	Example
FMW is generally helpful/relevant (14 participants, 62 references)	Positive feedback on program as a whole, without specifying particular module/topic/formatting aspect	"I was very happy with everything. It was refreshing to find something so straight forward and with so much information in the same place." (p14)
Positive feedback on specific content areas (13 participants, 92 references)	Positive feedback on specific content, specified by subtheme	
Emotional distress (8 participants, 14 references)		"I thought that was really good. Distress management was actually really, really good." (p5)
Worksheets/exercises (8 participants, 12 references)		"I thought they were very good and I went through some of those." (p13)
Meditation/relaxation (6 participants, 9 references)		"I really liked the relaxation exercises. That was perfect, to have them there. I hope I can still access it." (p10)
Clarifying questions (6 participants, 9 references)		"Week 1 had a lot of really good looking stuff in it. Getting your questions answered." (p11)
Video content (6 participants, 9 references)		"It was good to have some videos…It sort of breaks things up, so it's not all the same." (p10)
Supporting partners and families (5 participants, 7 references)		"I think it would probably hit the button for most people with breast cancer… Friends and family are the most important thing during your journey." (p9)
Physical symptoms (4 participants, 7 references)		"Anticipatory nausea and actually getting through that with chemo… that's a really good module to have in there' (p8)
Anecdotes (4 participants, 6 references)		"It's always really nice to hear other people that are in the same situation and how they're managing what their challenges are." (p8)
Self and identity (3 participants, 5 references)		"I thought…looking at yourself, because we kind of don't look in too much…I thought it was good to just have a little look and think about how would you speak to your body about having cancer" (p3)
Exercise and diet (2 participants, 3 references)		"Ongoing health plan is excellent, staying healthy after cancer" (p5)
Fatigue and sleep (2 participants, 3 references)		"Some of the parts where we were asked to work through issues, like the sleep thing, I found that was quite helpful." (p10)

Complementary therapies (2 participants, 2 references)		"The complimentary therapies module is good. It's sort of a non-judgemental nice and sort of, you know, objective." (p8)
Decision making (2 participants, 2 references)		"Decision making was also pretty good" (p10)
Sex and intimacy (2 participants, 2 references)		"Yeah, the intimacy stuff is very challenging for women with metastatic breast cancer, mainly dissatisfaction and how you feel about yourself. ..Excellent stuff you've got in there." (p8)
Some content remains relevant to ABC despite FMW's early stage focus (6 participants, 11 references)	Statement that FMW or parts of FMW are (still) relevant to ABC, recognising that this is the case even though FMW was designed for users with early stage cancer	"Even now, with advanced breast cancer, I am still dealing with fatigue, sleeping difficulties, pain, nausea and vomiting, loss of appetite, lymphedema, so it's all still relevant." (p15)
Recommended changes to content (14 participants, 282 references)		
Theme/subtheme	Definition	Example
Need for increased relevance to ABC (13 participants, 104 refs)	General statement that (some) content was not relevant to women with ABC and/or program needed additional content to be relevant to ABC	"I thought it had much that was useful, but it would require a major rethink if you to apply it to women with metastatic breast cancer. There was a lot that was sort of irrelevant." (p10)
Need to address ongoing/progression of treatment, instead of treatment completion (11 participants, 65 references)	Statement that parts of the program pertaining to treatment completion were irrelevant and/or would be better replaced with/supplemented by materials on ongoing treatment/progression of treatment	"…like the emphasis on survivorship and the assumed trajectory from, you know, diagnosis, treatment, recovery. That isn't applicable to women with metastatic cancer" (p10)
• *Needs content on palliative care and end-of-life* (6 participants, 23 references)	Suggestion/statement that program needs content on palliative care, end-of-life treatment and/or end-of-life decisions in or der to be (more) helpful to program users with ABC	"Probably almost like end of life decisions. When to make them? How to do it? Like, you know, advance care directives, even planning funerals, you know, it is a bit gloomy, but a lot of women do that." (p8)
• *Needs content on coping with mortality* (5 participants, 9 references)	Suggestion/statement that program needs (more) content on coping psychologically with mortality, i.e. coping with 'idea of' end of life	"When you reach stage 4, the biggest thing on your mind is the fear of dying. You know, that fear hits you like a brick wall. You're basically faced with your own mortality. That's really, *really* hard, to get through. You know, and that is a really, what I would call a top lying thing that needs to be addressed, the mortality." (p5)
Women with ABC already know about this content (8 participants, 17 references)	Statement indicating that women with ABC already know the information given in FMW content, with implication that content needs to be updated/expanded	"But what you've got on this site… we already know that." (p5)
• *Need depends on stage at diagnosis* (2 participants, 6 references)	Statement indicating those who have progressed to ABC after early stage diagnosis, and those with an initial diagnosis of ABC will have varying needs/knowledge	"There's two different kinds…one where women go from having early to secondary, and then… where you're diagnosed straightaway with advanced breast cancer" (p6)

• *Suggestion to break program into sections for different levels of knowledge depending on stage at diagnosis* (4 participants, 6 references)	Suggestion to have sections of program to give information depending on stage of disease and corresponding level of knowledge/needs at diagnosis	"you've got your three areas with early breast cancer, early breast cancer to secondary breast cancer, and then initial diagnosis of secondary breast cancer – they're the three main topics, and then from those three headings…have all your various other subject matter." (p6)
Didn't relate to content (8 participants, 20 refs)	Participant identifies content she did not relate to or find useful, without indicating that this was due to differences between ABC and early stage cancer focus of program	
Didn't like/relate to worksheets/activities (6 participants, 13 references)	Participant states she did not like or relate to worksheets/activities, or aspects of worksheets/activities	"Some of the worksheets I thought were perhaps just a bit much of a Band-Aid approach and not really providing anything concrete and I think…that's problematic with this sort of thing." (p10)
Doesn't feel need for psychological intervention (3 participants, 7 references)	Participant indicates she didn't find program particularly helpful due to not feeling the need for psychological help/intervention	"I feel that I'm dealing quite well with it, so I probably didn't [find it that helpful]." (p7)
Suggested additional content (13 participants, 169 references)	Participant identifies specific topics/areas in which she would like more program content (as per subtheme); not in specific context of difference between ABC and early stage cancer	
Accessing available resources (10 participants, 30 references)		"Just more relevant information on services available, like the local cancer centre, what they provide, like transport, things like that, things that I didn't know about before." (p12)
Coping with partner, family, friend responses (7 participants, 36 references)		"Navigating how to interact with your family and friends, particularly in the end stage, coz you might not wanna talk about it all the time, but on the other hand, you might have a family member that refuses to talk to you about it because they're not ready to deal with it." (p15)
Treatment and side effects (6 participants, 9 refs)		"Also, just information about the different forms of treatment…women want information about the different treatments and their side effects" (p10)
Exercise (5 participants, 9 refs)		"In Adelaide you can get access to some places that do exercise specifically for women that have had breast cancer…there's no such thing here in the country, and so if you could look at that on a video…like watching someone do Tai Chi lessons…that would be of massive benefit." (p4)

Managing pain (4 participants, 13 refs)	"You need more on pain meds…for women with advanced cancer." (p10)
Managing nausea (3 participants, 10 references)	"When you're talking about nausea, you only talk about anticipatory nausea which I thought was pretty strange even for women with un-advanced cancer because it's more the ongoing nausea that causes the problem." (p10)
Video tutorials (e.g. allied health) (3 participants, 9 refs)	"like a tutorial video about you, helping you feel good about yourself and even like a psychology point of view… what are you gonna do with yourself?" (p4)
Finances (3 participants, 7 references)	"Now the other thing is, again, information about finances. I don't think that's included anywhere in your overall program and yet for women in my position that can be very important in terms of income support, accessing insurance, superannuation, all that kind of stuff." (p10)
Living well, maximising time with ABC (3 participants, 7 refs)	"Yeah, living – it's not so much survivor stories, more it's living well with terminal cancer, you know, and that means… can mean, if you can afford, go off and do your holidays that you've always wanted to do." (p5)
Meaning of stage 4 diagnosis (3 participants, 4 references)	"When you're stage 4, well then you're going, 'Ok, what's going to happen now?'… that's what you look for as a newly diagnosed stage 4 – 'what is this going to mean for *me*?' How is this going to change my life? Yes, I'll be ill. But, can I actually have a life? Can I expect a life?" (p5)
Coping emotionally (3 participants, 3 references)	"At stage 4, because you tend to have way more anxiety, and anxiety always leads to depression… you need to know the resources to help you get through that, not just a pill…that is *really* common, those feelings are *really* common, particularly when you're first diagnosed stage 4." (p5)
Identifying legitimate information (2 participants, 7 references)	"Just to be careful… who you listen to." (p15)
Explanation of terms, glossary (2 participants, 4 references)	"That might be helpful…to have an explanation of difference between say a surgical oncologist and a medical oncologist, because some people might go: "What's the difference?" (p15)
Sex and intimacy (2 participants, 4 references)	'They need to know, they can access these things and if it is a problem, to go and see a gynaecologist. That is

		important to actually expand on it a little.' (p5)
Anecdotes (2 participants, 3 references)		"I like the anecdotal information, so more of that would be good" (p12)
Chat room, interaction (2 participants, 2 references)		"It would be good if it was more interactive. Have a chat room, but make it private and anonymous and confidential." (p12)
Feedback on use and navigation of *FMW* (15 participants, 247 references)		
Theme/subtheme	Definition	Example
Easy to use (15 participants, 75 references)	Includes references indicating that *FMW* or aspects of it are easy to use	
Easy to use (general) (14 participants, 25 references)	General statement/indication that *FMW* was easy/simple to use or not difficult to use	"So you could just step into it without any trouble. It took a little while, but nothing at all worrying. It was very simple." (p14)
Appropriate language (14 participants, 17 references)	Statement indicating that type/level language used in FMW program is appropriate/sufficiently easy to understand, or did not cause difficulty	"The language was excellent, really nice and clear and simple, just what you need when you're under the hammer." (p11)
Sufficient flexibility/self-pacing (11 participants, 20 references)	Statement indicating that level of flexibility to move around the program and self-pace was sufficient	"What was good was that it was broken down into simple steps… you can take a week to look at it…like diagnosis, you don't want to deal with that in one second. And physical symptoms… just that way of dividing it up and it's there, in front of you. You can look at that and you can go "I really don't feel like dealing with how I see myself. I might go back to emotional distress." (p11)
Appropriate module length (11 participants, 13 references)	Statement indicating that module length was appropriate, or did not cause difficulty	"I'd say just right. Not too short, not too long… it's not too much. Let me stress that, it's not too much." (p11)
Well set-up home screen (8 participants, 14 references)	Statement indicating positive experience of user home screen and/or of navigating to program content from the user home screen	"The way they're set up on that first page…you've actually got the sub-headings in there, which can take you pretty well straight to the basic of what you're looking for and then it expands, which is a really good idea." (p5)
Ease of internet format (2 participants, 3 references)	Statement indicating that participant found FMW easy to use or enjoyed using FMW due to the online format (as opposed to other, e.g. written, format)	"It's really nice to have something similar online so you can refer back to it and you can easily change things as your journey progresses because in the booklet form, you're writing down in pen and… if something changes, you know, you're crossing it out and writing something different in..." (p15)
Improvements needed to ease-of-use (13 participants, 110 references)	Includes references indicating difficulty using FMW or suggestion to improve experience of using FMW	

Navigation/layout issues (8 participants, 23 references)	Statement indicating that participant experienced problems/frustrations in viewing, navigating or using FMW due to program layout	"And it was like better…if you turn your tablet onto its side. The thing with the mood and fatigue graphs, you only got half of it, so that wasn't useful on my tablet at all." (p12)
Program/modules too long (7 participants, 25 references)	Statement indicating that participant found program or modules took too long to work through/complete	"Too many questions and… it just took too long to have to sit at the computer and go through everything." (p1)
Needs more flexibility for self-pacing (7 participants, 14 references)	Statement/suggestion indicating FMW would be improved by greater flexibility/choice in rate at which user progresses through the program, or in which sections or how much of the program to access at any one time	"If anyone's like me and they've got time on their hands… it would be nice to have the option… if you're ready to go and do some more, to have the option there. So, I think giving people the choice would be good." (p15)
Timing of complicating issues affected ease-of-use (4 participants, 16 refs)	Statement referring to difficulty using the program due to experiencing recent complicating issues such as disease progression, recent treatment	"In the place where I was when I started doing it, you know, if it was more than five words, I couldn't be bothered…" (p11)
Needs better indexing (3 participants, 13 refs)	Statement referring directly to need for better indexing or use of headings in order to easily/efficiently locate program content	"I think that it needs to be better indexed or you need to know what topics are actually going to be covered within the module a bit more clearly than the way you've done it at the moment." (p10)
Program too complicated (3 participants, 11 refs)	Statement describing difficulty using FMW due to finding it complicated, fussy or overwhelming, without directly stating this was due to navigation/layout issues (described above)	"You know when you're trying to deal with something and you just wanna go: "There. I want that information. I want it now. I don't want to muck around. I don't want somebody say "How are you feeling?", but I don't feel well at all…I don't want this fussy stuff!" (p11)
Issues for use and access (6 participants, 9 references)	Includes references in which participant identifies use/access concerns that may affect availability or effectiveness of FMW or future adaptations	
Needs to be well promoted for access (4 participants, 6 refs)	Suggestion or statement of concern that FMW or future adaptation of FMW will need to be well promoted in order for users to be aware of and able to access the program	"You know, so, but with advanced cancer… it needs to be known that it's there. And I mean, even the early one, needs to be known that it's there." (p5)
Needs to be kept relevant and up to date (2 participants, 3 references)	Reference indicating participant's concern/suggestion that FMW or future adaptation will need to be kept up to date in order to remain relevant and helpful to users	"I think that's important thing, keeping the information on there relevant and up to date because, as you know, cancer journey changes in a heartbeat…One day it will be this and then the next day they'll have a breakthrough and something else will happen and you can stop doing that and start doing this…" (p15)
Every woman with ABC is different (7 participants, 31 refs)	Includes references that indicate differences between women with ABC will affect their likely use of the program, need for various program content and features, and/or usefulness of program	

Varying preferences for information and support seeking (7 participants, 28 references)	Statement indicating that varying preferences for seeking information and support among women with ABC will affect whether, and how much, potential users will use and benefit from FMW or a similar ABC-specific program	"There's a lot of people out there who would never use this…purely because they're not that way inclined. They just go to the doctor and the doctor says 'do this' and they do that… And then you get people like me …I would definitely go for it because I would be looking for the information. (p5)"
• *Preference for face-to face therapy* (3 participants, 8 references)	Participant indicates they may not be inclined to use a program such as FMW due to a preference for face-to-face support	"I'm not sure that it would be particularly for me. I'm more someone that likes perhaps this type of help in terms of actually talking to somebody" (p6)
• *Difficulty using technology* (3 participants, 7 references)	Participant indicates concern that their own or others' difference in not liking or being confident using technology may affect use of the program	"Well, I'm not very good with technology. [laughs] Anyhow...I wouldn't have said that I've found it easy, that's for sure." (p4)
Differences in needs and in response to treatment (1 participant, 3 references)	Reference indicates that women with ABC have different needs and/or differences in disease progression or response to treatment and that this ought to be reflected in, or may affect usefulness of, a similar program for users with ABC	"It's just that women with advanced breast cancer… have different and unique needs, each and every one of us…and hopefully with what you're doing…you could sort of, shed some light on it, and give us access to different perspectives" (p6)
• *Coping with guilt/comparison with others* (1participant, 11 references)	Reference to comparing with women with ABC or with own past self, particularly reference to experiencing/coping with guilt on making such comparisons	"I do draw inspiration from women who are able to do that, but I've learnt that…I'm not a superwoman… I just do what I can do… I'm not answerable to anybody." (p6)
More support is needed for ABC (9 participants, 62 references)		
Theme/subtheme	Definition	Example
Feeling unsupported with ABC (7 participants, 16 references)	Participant indicates feeling unsupported or 'written off' due to the advanced status of their breast cancer and lack of resources available for ABC	"Yeah, just assuming that stage four is just oh, well, eventually you'll die, you know." (p1)
Need more studies of women with ABC (3 participants, 20 references)	Participant comments on lack of, or indicates desire for more, studies of women with ABC	"It's like no, there doesn't seem to be any studies out there… I'm talking about studies of women that are living really well with metastatic breast cancer." (p1)
Issues around appropriate terminology reflecting ABC status (3 participants, 11 references)	Participant indicates issues with terminology (e.g. 'palliative', 'survivor'), that contribute to feeling unsupported, misunderstood or excluded on account of ABC status	"I said "Don't say that…You need to find another word." You know, you've just been diagnosed…gotta find another word." (p1)
Lack of resources for rural ABC patients (3 participants, 10 references)	Participant comments on specific lack of resources for ABC patients residing in rural areas	"Yeah, the lack of, you know, being able to access, to physically access all that stuff that you're talking about or whatever, it's just so much harder in the country. [laughs]…and to have it there on, you know, the screen in front of you, is just almost like a relief I think." (p4)
Need more public understanding awareness of ABC	Participant comments on lack of, or need for more, public awareness and understanding of ABC, particularly in	"I think because everything is focused on women with early breast cancer… in the media, or…on television, it's all

(1 participant, 5 references)	context of comparison with public awareness and understanding of early stage breast cancer	focused at women with early breast cancer, and very, very rarely we see anything for women with advanced breast cancer" (p6)